Waxing and Waning

WAXING AND WANING: THE SHIFTING SANDS OF AUTONOMY ON THE MEDICO-LEGAL SHORE

Graeme T Laurie and J Kenyon Mason

School of Law, University of Edinburgh

Introduction

This chapter must begin with a confession; or, at least, the confirmation of an open secret. We share with Margaret Brazier a deep scepticism about the law's ability to give appropriate and meaningful moral force to the fundamental ethical principle of respect for autonomy. This will come as no surprise to any reader familiar with Brazier's work, or indeed ours. In this chapter, however, we want to combine forces (with the passive and unknowing input of Brazier by way of her scholarship) to argue that autonomy must come with responsibility. More particularly, this chapter focusses on autonomy within the family and the responsibilities that we all owe to each other within the family unit as genetically, and more socially, defined.

This choice of context is apt for a number of reasons. First, it reflects much of the scholarly contribution that Brazier has made over the decades to both medical law and family law. Secondly, the familial context provides a setting like no other in which to confirm John Donne's oft-quoted aphorism that 'no man is an island'. This is something that the law seems signally incapable of grasping, although there is development as we argue below. Thirdly, family relationships provide us with a particularly acute example of our necessarily social selves; we are dealing here not only with interconnections of individuals but also with pluralities of autonomies. Self-evidently, navigating such a social space cannot be done by reference to autonomy alone, yet the law often persists in a worldview that purports to do precisely this. We will demonstrate this through two paradigm examples of family relationships: the parent/child relationship and the genetic relationship. We will argue that medical law as it relates to the family can be best justified, and given greatest moral force, if we see autonomy as something that can be, and is, *tempered* by the responsibilities to others that it implies.

Brazier on autonomy and responsibility

Brazier began her 2006 contribution to the *Cambridge Law Journal* with the following quote:

> Towards the end of his judgment in *R. v. Collins and Ashworth Hospital Authority ex p. Brady*, Kay J. (as he then was) delivered the following homily: 'it would seem to me a matter of deep regret if the law has developed to a point in this area where the rights of a patient count for everything and other ethical values and institutional integrity count for nothing'.[1]

Brazier went on to argue that Kay J. *may* have been right. She lamented the dominance of autonomy that has arisen in medical law in the last few decades at the expense of other ethical imperatives such as beneficence, non-maleficence and justice. This trend has been well documented by many scholars.[2] Margot's ethical normative standpoint came easily: '[p]atients, people, have responsibilities to others which we neglect at our peril.'[3] However, her qualification as to the correctness of the honourable judge in *Brady* came not from ethical vacillation, but from the law itself: '…determining when the law should step in to enforce such responsibilities is much more difficult.'[4]

Let us begin with the points on which we agree with Brazier. Her position, as she herself points out, developed from the thinking of ethicists and philosophers such as Faden and Beauchamp,[5] and O'Neill,[6] who have long argued for a far richer notion of autonomy than is found in the current law of either the United Kingdom or the United States. Thus, elaborating on Faden and Beauchamp's view of autonomy as encompassing '...privacy, voluntariness, self-mastery, choosing freely, choosing one's own moral position and *accepting responsibility for*

---

1 Margaret Brazier, 'Do No Harm – Do Patients Have Responsibilities Too?' (2006) 65(2) Cambridge LJ 397-422, 397.

2 See, for example, Charles Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart Publishing 2009), and Jonathan Herring and Charles Foster, 'Welfare means Relationality, Virtue and Altruism' (2012) 32(3) LS 480.

3 Brazier (n 1) 398.

4 ibid.

5 Ruth Faden and Tom Beauchamp (in collaboration with Nancy M.P. King), *A History and Theory of Informed Consent* (Cambridge 1986).

6 Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge 2002). And see Onora O'Neill, 'Some Limits of Informed Consent' (2003) 29 JME 4.

one's choices…'.[7] Brazier argued that this last point, naturally, requires at least consideration of how one's choices will affect others. This is a quite modest demand, and one that is fairly incontrovertible so far as it represents a defensible moral position. However, the question Brazier asked was whether the law should attempt to enforce such a position, or rather, whether it should provide remedies if (moral) responsibilities are not discharged - and, here, we take some issue. This is not because it is a bad question per se, but we suggest that it asks the *wrong kind* of question about the relationship between autonomy and responsibility. To have responsibility does not necessarily imply (or require) the availability of a legal remedy – which, in turn, implies that someone else has a right. Rather, it can imply that there is an imperative for a richer – and thicker[8] – concept of autonomy itself. Brazier comes close to recognising this in her Cambridge article when she writes: '[m]y responsibilities may not translate into legal obligations. What identifying my ethical responsibilities may do is identify the limits of the obligation owed to me.'[9] It is this limiting or reconceptualising of the autonomy right – rather than the imposition of a (legal) responsibility – that we will now explore over, beginning with the parent/child relationship.

Autonomy and the parent/child relationship

We have discussed Brazier's pre-occupation with the interface between the legal and humanitarian aspects of autonomy elsewhere under the heading of autonomous humanity.[10] On reflection it would probably have been better to refer to 'humane autonomy', thus emphasising the close links between what we see as her unique brand of autonomy and what has become known as 'relational autonomy' or, more specifically, 'caring autonomy'.[11] It is trite to remark

---

7 Faden and Beauchamp (n 5) 7.

8 See, for example, Jørgen Husted, 'Autonomy and a Right Not to Know' in Ruth Chadwick, Mairi Levitt, and Darren Shickle (eds), *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility* (Cambridge 2014), 24.

9 Brazier (n 1) 413.

10 J Kenyon Mason, 'Autonomous Humanity? In Tribute to Margaret Brazier' (2012) 20 Med L Rev 150.

11 For which, see Katri Löhmus, *Caring Autonomy: Rethinking the Right to Autonomy under the European Court of Human Rights Jurisprudence* (Thesis, University of Edinburgh, 2013 – now in press). For criticism of the distinction of relational autonomy, see Sheila A M McLean, *Autonomy, Consent and the Law* (Routledge 2010) 214.

that circumstances alter cases and one of the difficulties in accepting either of the latter concepts lies in their inconsistency. Somewhere along the line, its protagonists must allow room for a balancing argument between, on the one hand, the entrenched legal reliance on individualistic autonomy as a baseline and, on the other, the strong human instinct to care for our fellows. What living relationship is more powerful than that of parent and child? Mighty few. Our contribution in this respect is to suggest that, counter to the legal dynamic and the majority of discussion in the literature that are both focussed on recognising the growing autonomy of the maturing child, we must also recognise the equal importance of the developing responsibilities that come with this tenet. Thus, just as autonomy develops and we are more self-reliant, so too do our responsibilities accumulate and we must be more cognisant of our immediate significant others and the impact of our choices on them.

As to autonomy per se, there is no dispute as to the upper end of the scale. Once a child has passed the age of 18, he or she becomes a legal adult and assumes individual autonomy and, given mental capacity, full sole responsibility for decisions as to health care.[12] It is clear, however, that development of capacity to make decisions for oneself is the result of a process. Essentially, then, the question of responsibility for the healthcare management of the maturing child resolves itself into the nature of the autonomy of the adolescent – and this has been one of Brazier's major target subjects.[13]

Although her seminal paper is now somewhat dated, we regard both the judicial and the statutory approach to adolescent autonomy as still unclear and this is largely due to difficulties – and laxity – in definition. What is adolescence? Most certainly, it is not a single moment in time; it is a series of moments – a transitional time – and as such it is better thought of as a process of transition than as a stable state of being. Indeed, many adults would regard adolescence *per se* as being distinctly unstable! Thus, this period has been helpfully defined as 'the process of developing from a child into an adult'.[14] Given this, there is no logical distinction to be made between a child and an adolescent – the frequent allusion to the age of 16 in both English and Scots family law represents no more than a legal convenience dictated

---

[12] Family Law Reform Act 1969, s 1.

13 Margaret Brazier and Caroline Bridge, 'Coercion or Caring: Analysing Adolescent Autonomy' (1996) 16 LS 84.

14 *Concise Oxford English Dictionary* (11th edn, revised 2008).

by the quest for clarity and certainty. Does it assist in the context of medical treatment, or does it merely cause confusion in the fields of parental responsibility and control of the legal minor as represented by the nearly-but-not-quite 16-year old, or the even less clear liminal space[15] between 16 and 18? This uncertainty is, perhaps, best expressed in the Family Law Reform Act 1969 where s 8(1) empowers the consent of the 16-year old to medical treatment while s 8(3) retains the effectiveness of any consent which would have been effective before the enactment of s 8(1) – which, as we have argued elsewhere, we believe is, basically, a reference to the parental responsibilities for legal minors.[16] The vast majority of medico-legal commentators, Brazier and ourselves included, deprecate the use of a calendar age as a measure of capacity – what matters is the patient's ability to understand the issues involved. We argue that this ability to understand includes the responsibility to appreciate the consequences of decisions on immediate significant others, most particularly family members. But how, then, have the courts grappled with this apparent conflict of interests introduced by statute? And is the problem, which distils into one between the individual autonomy of *children* and the caring autonomy of parents, finally resolved? We think not.

It is well-established that a review of the topic must start with *Gillick*[17] where the rights of a *child*, who is deemed to be capable of understanding the process and its likely consequences, to consent to medical treatment were confirmed, albeit by the narrowest of overall judicial support. It is equally well-known that the majority of resultant academic opinion was to the effect that the *Gillick* rule was, at least, undermined by the allied decisions in *Re R*[18] and *Re W.*[19] Enough ink has been spread over these cases as to render a further detailed description of them otiose in the present context. It is, however, relevant that we summarise our own, perhaps minority, view as to how far, if at all, they affect *Gillick*. We believe that they

---

15 A 'liminal space' is a space in-between, deriving from the Latin *limen*, meaning threshold. For the classic account of liminal spaces in human life, see Arnold van Gennep, *The Rites of Passage*, (Routledge and Kegan Paul 1960), especially chapter 5 (Birth and Childhood).

16 J Kenyon Mason and Graeme T Laurie, *Mason and McCall Smith's Law and Medical Ethics* (9th edn, 2013) para 4.61.

17 *Gillick* v *West Norfolk and Wisbech AHA* [1985] 3 All ER 402, HL.

18 *Re R (a minor)(wardship: medical treatment)* [1992] Fam 11.

19 *Re W (a minor)(medical treatment)* [1992] 4 All ER 627.

carry different messages. Insofar as locking and unlocking doors involves activity, Lord Donaldson's metaphor of multiple key holders to consent to treatment of minors in *Re R* certainly raises the implication that parents may legally interfere with the wishes of the mature – or *Gillick*-competent – minor, at least when it comes to refusal of treatment and care. The analogy was, however, replaced in *Re W* by that of the flak-jacket, the donning of which is a purely passive, protective exercise. Yes, the metaphorical ack-ack gunner is the litigious child but we take issue with Brazier who concluded that Lord Donaldson impliedly 'condemns' hospitals for accepting the protection offered.[20] Rather, he is opening the way to conscientious medical practice in the case of a vulnerable patient. *Re W* resolves a medical dilemma and *Gillick* is, thereby, undisturbed.

Clearly, then, whether or not the doctor accepts the proffered 'flak-jacket' depends to a large extent on the severity of the condition to be treated - and the end of the line is to be found in a clinical choice between life and death where the courts will, in general, prefer professional expertise to the autonomy of the *Gillick*-competent minor.[21] In fact, if our analysis is correct, the courts *need* be involved only rarely – when both the competent minor and his or her parents refuse treatment against strong medical advice,[22] or when parents plead responsibility and insist on treatment in the face of competent minor refusal. We suggest that there are ways to resolve these apparent conflicts that reduce the superficial dichotomisation of the issues at stake. If parents and child are in agreement as to the correct course of action, we have, arguably, an instance of 'family autonomy'. This is not a concept that is recognised by the British courts, but it has held sway in Ireland and has been deployed by the Supreme Court to support resistance to state-endorsed interference in family life.[23] This is not to suggest that this can never be overridden but, rather, that the unity of the family sets up a strong prima facie presumption – bolstered by the plurality of autonomies raised in one voice – that necessitates overwhelming

---

20 Brazier and Bridge (n 13) 87.

21 See, for example, the high profile case of *Re M (child: refusal of medical treatment)* [1999] 2 FLR 1097 – refusal of a heart transplant. And, in general, see Emma Cave, 'Maximisation of Minors' Capacity' (2011) 23 CFLQ 41.

22 For which see the paradigmatic Jehovah's Witness case of *Re E (minor)* [1993] 1 FLR 386.

23 Graeme Laurie, 'Better to Hesitate at the Threshold of Compulsion: PKU Testing and the Concept of Family Autonomy in Eire' (2002) 28(3) JME 136.

evidence of benefit both to the child and to the family unit, before it can be legitimately set aside.

Contrariwise, where there is apparent conflict between parents and child, this is usually viewed as an expression of parental responsibility *versus* child autonomy. It need not be thus. For example, to encompass holistically the role of autonomy it might be preferable to consider the caring autonomy of the parents *together with* the individual autonomy of the child. Alternatively, we might consider the responsibilities of the parents towards their child with the responsibilities of the child towards his or her parents. What, we might ask, precisely are these responsibilities? At base, they are a duty to care about the consequences of our decisions on others, and to take this into account in decision-making. The common feature here – whether we cast the issues as autonomies *and* responsibilities – is the bond of care within the family unit. We suggest, moreover, that it is preferable to level the playing field by identifying what is at stake and thereby comparing like-with-like - for example considering, simultaneously, the range of responsibilities and the pluralities of autonomies. In turn, this can help to reveal shared concerns rather than contentious conflict. To do so might further assist in keeping the courts out of family life.

The child incapax

This still leaves open – indeed, raises - the question of parental *responsibility* for assuming the autonomous mantle of the child who is unable to express him- or herself by reason of incapacity. This is a wide aspect of autonomy that involves the whole spectrum of the parent/child relationship including that of the child *in utero*. It is now self-evident, for example, that a competent woman is under no obligation to alter her life-style for the benefit of her fetus;[24] nor has she an obligation to undergo treatment for that purpose.[25] But what if the maternal/fetal conflict is of a social – e.g. religious - rather than a medical nature? At what point does a maternal decision as to her fetus or neonate become irresponsible?[26] In the UK, a fetus has no

24 *Re F (in utero)* [1988] Fam 122, and more recently *CP (a child) v Criminal Injuries Compensation Authority* [2014] EWCA Civ 1554.

25 *St George's Healthcare NHS Trust* v *S* [1998] 3All ER 673.

26 This question should not be confused with the decision to terminate pregnancy within the law. We might, better, consider at what point does Government interference with fetal or neonatal autonomy become

legal rights until it is born alive and this is also a tenet of European human rights law. But, what of the pregnant woman who chooses to continue pregnancy? What obligations does she owe to her *future* child? Indeed, what obligations do parents, in general, owe to their children as, hopefully, *future* autonomous persons?

Once again, we contend that autonomy and responsibility are inseparable concepts.[27] The relationship can be seen as one of ebb and flow, the *temporary* immaturity of the person being a strong influence on the force of the tide. As our maturity deepens, so our entitlement to recognition of autonomy strengthens. This fluid continuum, is not, however, one that law tends to recognise as robustly as it could. Law compartmentalises us into status silos of 'parenthood' and 'childhood', refusing to see that these are contingent states. The implications for responsibility and autonomy of recognising this are profound. Even so, there is now little doubt as to the common law understanding of responsibility for the welfare of the infant. Baker J has recently expressed this without equivocation:

> It is a fundamental principle of family law in this jurisdiction that responsibility for making decisions about a child rest with his parents. In most cases, the parents are the best people to make decisions about a child and the State – whether it be the court, or any public authority – has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.[28]

These words arose in the unusual case of Ashya King, whose parents found themselves at the uncomfortable end of both family and criminal law for seeking to act on their own view of their child's best interests by removing him from the UK in a desperate attempt to seek effective treatment.[29] The invocation of wardship jurisdiction and the European Arrest Warrant violently

---

unacceptable? See Sheila A M McLean and J Kenyon Mason, 'Our Inheritance, Our Future: Their Rights?' 2005) 13 Int J Child Rights 255.

27 Thus emphasising the oft-forgotten fact that children develop increasing responsibility to their parents as they mature.

28 *Aysha King (a child), Re* [2014] EWHC 2964 (Fam), per Baker J at para 31.

29 Leading Article, 'Hard Cases', (2014) *The Times*, 2nd September, 28.

disrupted the family dynamic in this case. Our analysis suggests that the family-faced-with-futility scenario should not lightly be labelled in the category of abusers. This is because we argue here that parental responsibility should not be seen solely as provision of immediate term care; instead it should be revisioned also as a charge to promote the chance of *future* autonomy. This extrapolation of Brazier's arguments, we wager, would lead many observers to take a very different view of such a troubling case and of the parent/child relationship more generally.

Responsibilities to autonomous others

It is a further truism that the bonds of family do not necessarily bind as tightly once the parenthood-childhood dynamic is a thing of the past. But, equally axiomatically, family ties connect us to others beyond the vertical maternal/paternal relationship. Horizontal connections to siblings, cousins, and even relatives-in-law, have moral meaning for a variety of reasons, but few are so potentially powerful as the genetic ties between us. This example provides the focus for the second half of this chapter, in which we intend to do no more than emphasise the reality that *some* forms of genetic information – such as highly predictive, recessive or dominant treatable disorders – can have significant consequences for our immediate family. This is true both in terms of the health and well-being of blood relatives who might have an interest in knowing 'familial' genetic information, and also for those related through law or by the common enterprise of continuing the family - that is, that future reproductive choices can also found claims to an interest in knowing familial genetic information.

We have argued elsewhere about the rights and responsibilities relating to genetic information, and we will not repeat those arguments.[30] Our contribution here is to suggest that ethics, professional guidance and, even, law are far more in alignment about giving effect to the responsibilities arising from the generation of genetic knowledge than the 'tyranny of autonomy'[31] caricature might lead us to believe. Brazier argued that '…a family member holding information crucial to the good health of his or her relatives owes an ethical obligation

30 See Graeme Laurie, *Genetic Privacy: A Challenge to Medico-legal Norms*, (Cambridge University Press 2002), and more recently, Graeme Laurie, 'Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications' (2014) 42(1) J Med Law and Ethics 53, and Graeme Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity', in Chadwick, Levitt, Shickle (n 8) 38.

31 We borrow here from the excellent title of Charles Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (n 2).

to consider sharing that information.'[32] This is extensively supported in the clinical[33] and ethical literature,[34] and it is a view with which we take little issue. However, and once again, whither the law in all of this? Brazier considered whether there is a legal *obligation* to share genetic information, examining, first, whether there is a duty of care in negligence to family members likely to be affected by genetic disease,[35] and second, whether there is a professional duty or discretion to disclose.[36] In typical prescient fashion, Brazier noted:

> If it is *my* relatives who are of [sic] risk because of *our* heritage, the responsibility to act to protect those family members is primarily mine. Professionals can and should inform and advise me to assist me to discharge my ethical responsibilities. I cannot shuffle off responsibility to them."[37] [emphasis in original]

More recently, this has been confirmed as a matter of everyday practice by the Joint Committee on Medical Genetics that has pointed out:

> …there are significant practical hurdles in contacting a range of relatives who may be difficult to identify and locate. For these reasons, current UK genetic practice largely leaves the onus of communication with the individual first diagnosed.'[38]

---

32 Brazier (n 1) 410.

33 Belinda Rahman et al., 'To Know or Not to Know: An Update of the Literature on the Psychological and Behavioral Impact of Genetic Testing for Alzheimer Disease Risk' (2012) 16(8) Genetic Testing and Molecular Markers, 1, and Jan Hodgson and Clara Gaff, 'Enhancing Family Communication About Genetics: Ethical and Professional Dilemmas' (2013) 16 Journal of Genetic Counselling 16.

34 Nina Hallowell et al., 'Balancing Autonomy and Responsibility: The Ethics of Generating and Disclosing Genetic Information' (2003) 29 JME 74; Michael Parker and Anneke Lucassen, 'Genetic Information: A Joint Account?' (2004) 329 BMJ 165.

35 We first considered this in Graeme Laurie, 'Obligations Arising from Genetic Information - Negligence and the Protection of Familial Interests' (1999) 11 CFQ 109.

36 Brazier (n 1) 412-413.

37 Ibid 413.

38 Royal College of Physicians, Royal College of Pathologists and British Society of Human Genetics, *Consent and Confidentiality in Clinical Practice: Guidance on Genetic Testing and Sharing Genetic Information*', (2nd edn 2011), available at: https://www.rcplondon.ac.uk/sites/default/files/consent_and_confidentiality_2011.pdf

Legal attention on the relevant rights and responsibilities has also increased since Brazier's own analysis, becoming bolder in the conviction that law *could* be made to enforce familial responsibilities. Thus, for example, we have Fay arguing for a common law duty of care on the part of clinicians when there is 'effective treatment' for an 'identifiable victim', i.e. first order family members at highest risk.[39] Similarly, Foster et al. have suggested that the balancing of human rights considerations under the Human Rights Act 1998 - between Article 8 (right to respect for private and family life) and Article 10 (freedom of expression) - would 'mandate' that a version of a 'joint account model'[40] of familial genetic information be deployed.[41] But, of course, herein lies the rub. The courts in the United Kingdom have not yet considered any of these disclosure dilemmas, but the arguments to recognise autonomy and responsibility as symbiotically connected would now be difficult to resist.

Further afield, and in the context of data protection legislation, the European Article 29 Data Protection Working Party has indicated that:

> To the extent that genetic data has a family dimension, it can be argued that it is 'shared' information, with family members having a right to information that may have implications for their own health and future life…The precise legal consequences of this argument are not yet clear. At least two scenarios can be imagined. One is that other family members could also be considered as 'data subjects' with all the rights that follow from this. Another option is that other family members would have a right of information of a different character, based on the fact that their personal interests may be directly affected. However, in both scenarios further options and conditions would have to be considered to accommodate the various conflicts that are likely to arise

---

39 Michael Fay, 'Informing the Family: A Geneticist's Duty of Care to Disclose Genetic Risks to Relatives of the Proband' (2011) 27(2) Prof Neg 97.

40 See Parker and Lucassen (n 34). Foster et al. suggest a modified version that reflects the communitarian and feminist-based argument in Roy Gilbar and Sivia Barnoy, 'Disclosure of Genetic Information to Relatives in Israel: Between Privacy and Familial Responsibility' (2012) 31 New Gen and Soc 391.

41 Charles Foster, Jonathan Herring and Magnus Boyd, 'Testing the Limits of the 'Joint Account' Model of Genetic Information: A Legal Thought Experiment' (2014) JME, Published Online First: 25 June 2014, doi:10.1136/medethics-2014-102142.

between the different claims of family members, either to have access to information or to keep it confidential.[42]

The Icelandic Supreme Court has already recognised the interest that a family member has in having a say over a deceased relative's personal data for the potential implications this might have for her.[43] Moreover, the current draft proposals for a European Data Protection Regulation now expressly mention 'genetic data' as a sub-set of 'personal data' to be protected,[44] albeit that they do not attempt to resolve the responsibility dilemma highlighted by the Article 29 Working Party (above). Our preference would be for express acknowledgement of the familial nature of (some) genetic information in *both* of the respects that we have argued for above, viz, not only that family members might have 'rights' as data subjects (albeit in a modified form), but also that the exercise of any rights with respect to 'personal' data can be curtailed if processing is necessary in the 'vital interests' of a family member. At present, the Data Protection Directive and the draft General Data Protection Regulation allow processing in the interests of a data subject or of the public interest, but this is insufficiently specific in the context of our present discussion. To incorporate this proposal would bring legal recognition to a social and medical reality that uniquely affects the family unit.[45] But, equally, we caution against putting too much faith in law, as the next example demonstrates.

---

42 Article 29 Data Protection Working Party, *Working Document on Genetic Data* (2004), available at: http://ec.europa.eu/justice/policies/privacy/docs/wpdocs/2004/wp91_en.pdf

43 For discussion, see Rena Gertz, 'Is it 'Me' or 'We'? : Genetic Relations and the Meaning of 'Personal Data' under the Data Protection Directive' (2004) 11(3) Euro J Health Law 231. Note, however, the provisions of the European Data Protection Directive do not extend to the personal data of deceased persons.

44 Draft Regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (Brussels, 25.1.2012, COM(2012) 11 final) draft Articles 4(1), 4(10), 9(1), and 33(2).

45 For an excellent account on data, see Mark Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge University Press 2012). On inconsistencies between data and tissue, see Graeme T Laurie and Shawn HE Harmon, 'Through the Thicket and Across the Divide: Successfully Navigating the Regulatory Landscape in Life Sciences Research', in Emilie Cloatre and Martyn Pickersgill (eds), *Knowledge, Technology and Law*, (Routledge 2014) 121. The Article 29 Group has recently confirmed its view that '…health data also include "information derived from the testing or examination of a body part or bodily substance, including biological samples" [reflecting the draft General Data Protection Regulation]', see Letter from the Article 29 WP to the European Commission, DG CONNECT on mHealth, available at: http://ec.europa.eu/justice/data-protection/article-29/documentation/other-document/index_en.htm (5 February 2015).

Some jurisdictions have attempted to give legal effect to the responsibilities that vex us. We have discussed the position at common law in some of the United States elsewhere.[46] More recently, Australia has legislated to amend its Privacy Act 1988 to allow disclosures of genetic information to family members for similar motives outlined herein.[47] The law now permits a healthcare organisation to disclose genetic information where it:

> …reasonably believes that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety (whether or not the threat is imminent) of an individual who is a genetic relative of the individual to whom the genetic information relates… (s 5, introducing Schedule 3.2.1(e) to the Guidelines for national Privacy Principles about genetic information).

This move has, however, been subject to sustained criticism.[48] Technical and practical issues of drafting and legislative interplay have meant that actual action on information available to healthcare professionals is restricted, while definitional and ethical concerns plague the legislation. For example, what precisely does the term 'genetic' encompass, and is this different from 'familial' information? Furthermore, what will constitute a 'serious threat', and what of non-genetic relatives whose reproductive choices might also be impacted with significant downstream implications for future persons? Finally, and to return to an issue that has occupied us for many years, what about the important claim that some people would prefer *not* to know? We should be very careful in the climate of this discussion not to suggest that the relationship between responsibility and autonomy necessarily means that there is *always* a responsibility to attempt to *promote* autonomy. As our chapter title suggests: just as the moon has its influence on the tides, so too must we face the consequences of recognising more responsibilities when it comes to autonomies. Legal attempts to proscribe on the vagaries may be doomed to failure.

Conclusion

---

46 Mason and McCall-Smith's *Law and Medical Ethics* (n 16) ch.7.

47 See the Privacy Legislation Amendment Act 2006.

48 Wendy Bonython and Bruce Arnold, 'Disclosure 'downunder': Misadventures in Australian Genetic Privacy Law' (2014) 40 JME 168, and Margaret Otlowski, 'Australian Reforms Enabling Disclosure of Genetic Information to Genetic Relatives by Health Practitioners' (2013) 21(1) J Law Med 217.

Our conclusion on this discussion of the interplay between medical law and family law neatly mirrors the position that Margot Brazier has outlined in her work, and which we identify above: 'If it is *my* relatives who are of [sic] risk because of *our* heritage, the responsibility to act to protect those family members is primarily mine.'[49] As we have argued, these responsibilities are essentially a *communal/familial* consideration, not restricted to genetic relations. Moreover, we favour only a marginal role for law in achieving this. As the last example demonstrates, even if we try to give effect to responsible conduct when it comes to promoting the autonomy of others, there is no substitute for taking moral responsibility for the ones we love. We sincerely hope that Brazier would agree.

[49] Brazier (n1) 413.